

AMENDMENT IN THE NATURE OF A SUBSTITUTE
TO H.R. 3034
OFFERED BY MR. BILIRAKIS

Strike all after the enacting clause and insert the following:

1 SECTION 1. SHORT TITLE.

2 This Act may be cited as the “National Bone Marrow
3 Donor Registry Reauthorization Act”.

4 SEC. 2. NATIONAL BONE MARROW DONOR REGISTRY.

5 (a) NATIONAL REGISTRY.—Section 379 of the Public
6 Health Service Act (42 U.S.C. 274k) is amended—

7 (1) in subsection (a)—

8 (A) in paragraph (1), by striking “except
9 that” and all that follows and inserting “except
10 that—

11 “(A) such limitations shall not apply to the
12 Chair of the board (or the Chair-elect) or to the
13 member of the board who most recently served
14 as the Chair; and

15 “(B) 1 additional consecutive 2-year term
16 may be served by any member of the board who
17 has no employment, governance, or financial af-
18 filiation with any donor center, recruitment



1 group, transplant center, or cord blood bank.”;
2 and

3 (B) in paragraph (4)—

4 (i) by striking “the Naval Medical Re-
5 search and Development Command” and
6 inserting “the Department of Defense
7 Marrow Donor Recruitment and Research
8 Program operated by the Department of
9 the Navy”; and

10 (ii) by striking “Organ” after “Divi-
11 sion of”;

12 (2) in subsection (b)—

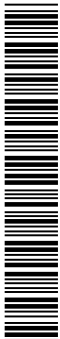
13 (A) in paragraph (4), by inserting “at
14 least” before “annually”;

15 (B) in paragraph (7), by striking “and
16 comparisons of transplant centers regarding
17 search and other costs that prior to transplan-
18 tation are charged to patients by transplant
19 centers; and”;

20 (C) in paragraph (8), by inserting “and
21 outreach” after “and demonstration”;

22 (D) at the end of paragraph (8), by strik-
23 ing the period and inserting a semicolon;

24 (E) by redesignating paragraphs (3)
25 through (8) as paragraphs (4) through (9);



1 (F) by inserting after paragraph (2), the
2 following:

3 “(3) maintain and expand medical emergency
4 contingency response capabilities in concert with
5 Federal programs for response to threats of use of
6 terrorist or military weapons that can damage mar-
7 row, such as ionizing radiation or chemical agents
8 containing mustard, so that the capability of sup-
9 porting patients with marrow damage from disease
10 can be used to support casualties with marrow dam-
11 age;”; and

12 (G) by adding at the end the following:

13 “(10) conduct and support research to improve
14 the availability, efficiency, safety, and cost of trans-
15 plants from unrelated donors and the effectiveness
16 of Registry operations;

17 “(11) increase the number of umbilical cord
18 blood units listed in the Registry and assist cord
19 blood banks in the Registry program in accordance
20 with subsection (c); and

21 “(12) establish bylaws and procedures—

22 “(A) to prohibit any member of the board
23 of directors of the Registry who has an employ-
24 ment, governance, or financial affiliation with a
25 donor center, recruitment group, transplant



1 center, or cord blood bank from participating in
2 any decision that materially affects the center,
3 recruitment group, transplant center, or cord
4 blood bank; and

5 “(B) to limit the number of members of
6 the board with any such affiliation.”;

7 (3) in subsection (c)—

8 (A) in clause (ii) of paragraph (2)(A), by
9 striking “, including providing updates”; and

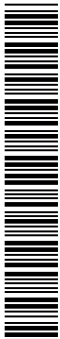
10 (B) in paragraph (3), by striking “the
11 availability, as a potential treatment option, of
12 receiving a transplant of bone marrow from an
13 unrelated donor” and inserting “transplants
14 from unrelated donors as a treatment option
15 and resources for identifying and evaluating
16 other therapeutic alternatives”;

17 (4) in subsection (d)—

18 (A) in paragraph (2)(C), by inserting “and
19 assist with information regarding third party
20 payor matters” after “ongoing search for a
21 donor”;

22 (B) in paragraph (2)(F)—

23 (i) by redesignating clause (v) as
24 clause (vi); and



1 (ii) by inserting after clause (iv) the
2 following:

3 “(v) Information concerning issues
4 that patients may face after a transplant
5 regarding continuity of care and quality of
6 life.”; and

7 (C) in paragraph (3)(B), by striking “Of-
8 fice may” and inserting “Office shall”;

9 (5) in subsection (g), by striking “the bone
10 marrow donor program of the Department of the
11 Navy” and inserting “the Department of Defense
12 Marrow Donor Recruitment and Research Program
13 operated by the Department of the Navy”;

14 (6) in subsection (h)—

15 (A) by striking “APPLICATION.—” and in-
16 serting “CONTRACTS.—”;

17 (B) by striking “To be eligible” and insert-
18 ing the following:

19 “(1) APPLICATION.—To be eligible”; and

20 (C) by adding at the end the following:

21 “(2) CONSIDERATIONS.—In awarding contracts
22 under this section, the Secretary shall give substan-
23 tial weight to the continued safety of donors and pa-
24 tients and other factors deemed appropriate by the
25 Secretary.”;



1 (7) in subsection (i), by striking “include” and
2 inserting “be”; and

3 (8) by striking subsection (l).

4 (b) BONE MARROW SCIENTIFIC REGISTRY.—Section
5 379A of the Public Health Service Act (42 U.S.C. 274l)
6 is amended—

7 (1) in subsection (a), by adding at the end the
8 following: “The scientific registry shall participate in
9 medical research that has the potential to improve
10 transplant outcomes.”;

11 (2) in subsection (c), by striking “Each such re-
12 port shall in addition include the data required in
13 section 379(l) (relating to pretransplant costs).”;
14 and

15 (3) by adding after subsection (c) the following:

16 “(d) PUBLICLY AVAILABLE DATA.—The scientific
17 registry shall make relevant scientific information not con-
18 taining individually identifiable information available to
19 the public in the form of summaries and data sets to en-
20 courage medical research and to provide information to
21 transplant programs, physicians, and patients.”.

22 (c) BONE MARROW AND MARROW DEFINED.—Part
23 I of title III of the Public Health Service Act (42 U.S.C.
24 274k et seq.) is amended—



1 (1) by redesignating section 379B as section
2 379C; and

3 (2) by inserting after section 379A the fol-
4 lowing:

5 **“SEC. 379B. BONE MARROW AND MARROW DEFINED.**

6 “For purposes of this part, the terms ‘bone marrow’
7 and ‘marrow’ include bone marrow and any other source
8 of hematopoietic progenitor cells the acquisition or use of
9 which is not inconsistent with Federal law.”.

10 (d) AUTHORIZATION OF APPROPRIATIONS.—Section
11 379C of the Public Health Service Act, as redesignated
12 by subsection (c), is amended to read as follows:

13 **“SEC. 379C. AUTHORIZATION OF APPROPRIATIONS.**

14 “(a) IN GENERAL.—For the purpose of carrying out
15 this part, there are authorized to be appropriated
16 \$32,000,000 for fiscal year 2004, and such sums as may
17 be necessary for each of the fiscal years 2005 through
18 2008.

19 “(b) EMERGENCY CONTINGENCY RESPONSE CAPA-
20 BILITIES.—In addition to any amounts authorized to be
21 appropriated under subsection (a), there are authorized to
22 be appropriated such sums as may be necessary for the
23 maintenance and expansion of emergency contingency re-
24 sponse capabilities under section 379(b)(3).”.

